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ABSTRACT

This paper reports the findings of a study that examined where and how children with autistic spectrum disorders are being educated in Scotland. The study specifically sought: (1) to identify the number of children reported to have autistic spectrum disorders and their type of educational placements; (2) to identify the types of educational practice with respect to these children and to highlight issues of satisfaction or concern with the practices; and (3) to identify good practice in the education of these pupils and to make recommendations. Questionnaires and interviews of professionals and parents provided the necessary information. Results of the study showed rates of identification that significantly under-represented the numbers of children with autistic spectrum disorders, as calculated from prevalence rates. Findings also indicated the percentage of children with autistic spectrum disorders in special schools was shown to increase rapidly in early childhood and reach a peak at six years. Also, the majority of parents were either satisfied or very satisfied with their child's current educational situation. The study was able to provide a clear educational definition of autistic spectrum disorders and emphasize the distinction between a medical diagnosis and special educational needs. (CR)

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THE SCOTTISH OFFICE

Education and Industry Department

INTERCHANGE

No 46

Educational Provision for Children with Autism in Scotland

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EDUCATIONAL PROVISION FOR CHILDREN WITH AUTISM IN SCOTLAND

Rita Jordan and Glenys Jones

School of Education, The University of Birmingham

There is a growing body of evidence that children with autism and Asperger syndrome have specific needs which require a different focus and approach from those adopted for children with other types of special educational need. In response to this, The Scottish Office Education and Industry Department commissioned the University of Birmingham to investigate the educational opportunities for children with autistic spectrum disorders in Scotland. The project was conducted between August 1995 and August 1996.

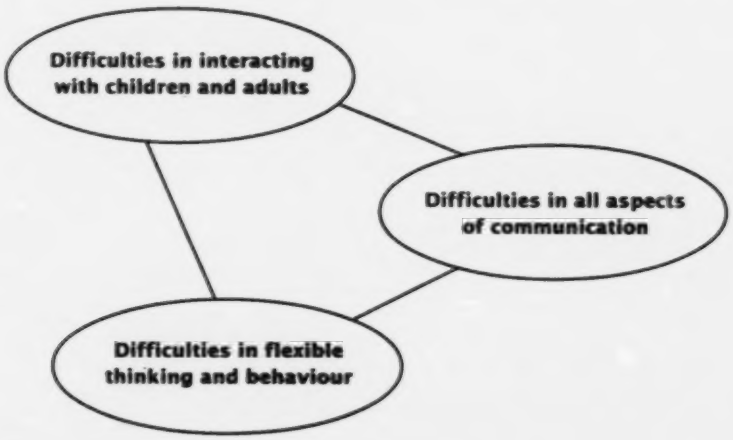
The Research

The research aims were:

- to identify the number of children reported to have autistic spectrum disorders in Scotland and the type of educational placements they attended;
- to identify the kinds of educational practice with respect to these children and to highlight any issues of satisfaction or concern with those practices, as expressed by parents and professionals;
- to identify good practice in the education of these pupils and to make recommendations based on examples of good practice in Scotland and elsewhere.

An educational definition of autism was developed to identify children who need specific forms of education, regardless of whether there was a formal diagnosis of an autistic spectrum disorder. The definition was based on the triad of impairments (see Figure 1). It was stressed that all aspects of the triad must be present before a child could be described as having an autistic spectrum disorder.

Figure 1: The triad of impairments found in children with autistic spectrum disorders including Asperger syndrome


Difficulties in interacting with children and adults
Difficulties in all aspects of communication
Difficulties in flexible thinking and behaviour

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Questionnaires were sent to professionals with a key role in identifying children with autistic spectrum disorders and/or making provision for them. There were four groups:

- Directors of education
- Area principal educational psychologists
- Educational psychologists
- Headteachers or teachers-in-charge of all special schools and units, including those which were said to specialise in autism

Parents, contacted through voluntary societies and through schools, were also sent a questionnaire and the research team visited a selection of schools, units and families.

The survey coincided with a reorganisation of local government in Scotland. This not only affected people's ability or willingness to respond to the questionnaires used in the survey, but also meant that the pattern of services existing at the time of the interviews and visits was changing. It will continue to change as new authorities assess the provision they have inherited and their own needs in relation to their own policies.

Prevalence of autistic spectrum disorders in children

There are three prevalence rates, based on an increasingly wider definition of autism, informing epidemiological research. The rates are 5/10,000 for 'Kanner's autism', 22/10,000 for a wider group, and 58/10,000 for the full range of autistic spectrum disorders including Asperger syndrome. The prevalence rates for each year group will vary from these as very young children will not have been diagnosed and the rate will be lower for older children as diagnostic criteria for autism were likely to have been more narrowly defined in the past. It is not easy to identify how many children with autistic spectrum disorders there are with recognised special educational needs, and where they are placed educationally by an education authority. This is because of the difficulties with identification and diagnosis, attitudes about using labels for particular groups of children, the knowledge and experience of professionals involved and the fact that the data are not held centrally.

It is possible to calculate the estimated number of children with autistic spectrum disorders living in a particular education authority by taking epidemiologically-based prevalence figures and using the population estimates for children aged 0 to 19 years. In Table 1, the two rates of 5/10,000 and 22/10,000 are given as the basis for comparison with the results obtained in this survey.

Overall, only 29% of the children expected at the prevalence rate of 22/10,000 were identified – but the range was wide between authorities. It is difficult to see a clear pattern in the different prevalence rates between authorities (16-63%). Neither size nor rural characteristics were good discriminators of identification

Table 1: Number of children with autism expected from the two different prevalence rates and the actual number identified

Education Authority (EA)	Child population estimate (0-19 yrs)	Number based on prevalence 5/10,000	Number based on prevalence 22/10,000	Actual number identified	Percentage of 5/10,000	Percentage of 22/10,000
EA 1	23,184	12	51	19	158%	37%
EA 2	65,471	42	144	36	86%	25%
EA 3	34,547	17	75	12	142%	16%
EA 4	85,835	42	188	67	159%	63%
EA 5	127,406	63	279	140	222%	50%
EA 6	53,559	26	117	63	242%	54%
EA 7	169,489	84	372	109	129%	29%
EA 8	5,106	3	11	6	200%	55%
EA 9	6,208	3	13	4	133%	31%
EA 10	565,873	282	1,244	285	101%	23%
EA 11	92,911	46	204	36	78%	18%
EA 12	7,465	3	16	3	100%	19%
Total	1,237,054	618	2,721	780	126%	29%

rates. A more likely explanation will be in terms of availability of expertise in relation to the size of the population, but the research could not determine this.

The results of this research showed rates of identification that significantly under-represent the numbers of children with autistic spectrum disorders, calculated from prevalence rates. However, a distinction needs to be drawn between medical or scientific prevalence rates and prevalence of particular special educational needs. It is important that particular rates are not seen as target figures for the identification of special educational needs arising from autistic spectrum disorders.

The number of children with autistic spectrum disorders identified was well below the prevalence rates (even when low response rates were taken into account).

Of 294 children in special schools or units identified as having an autistic spectrum disorder, 15% were said by respondents to have Asperger syndrome. The current prevalence figure for Asperger syndrome is 36/10,000, which should lead to a higher number of children with Asperger syndrome than autism, overall. However, this sample was taken from special schools and units and one would expect that many children with Asperger syndrome, because of their higher intellectual ability, would be attending mainstream schools. Unfortunately, data from educational psychologists about children in mainstream was very sparse, so that it was not possible to calculate what percentage of the Asperger population attended mainstream school compared to a special unit or school.

How can authorities enhance the ability of professionals to identify the special needs of children with autistic spectrum disorders including Asperger syndrome?

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The implications of early diagnosis

Helpful advice to parents on autism and provision to meet special educational needs after the diagnosis was not always provided.

What can be done to ensure that appropriate advice and support is made as soon as possible after the diagnosis?

Many children in Scotland were being diagnosed before the age of 5 years. However, there was often a gap between diagnosis and educational advice. Some professionals felt that diagnostic centres were not always knowledgeable about services within an authority. There is, then, a need for closer communication between those making the diagnosis and educational providers. The moves in some authorities to establish multidisciplinary assessment teams to make an educational assessment of need should be encouraged. However, such teams are more likely to get the support of parents, and be useful to practitioners, if they accept the usefulness of the diagnosis of autism and do not rely on descriptions based on one area of impairment (such as 'communication disorder'). Some respondents, for example, felt it was not necessary to know that a child had autism or Asperger syndrome and that it sufficed to describe the child in terms of their main areas of difficulty – yet such descriptions on their own are less helpful to parents and teachers, as they give no information as to *why* the child has these difficulties.

Range of educational provision

Children with autism may be found within any kind of provision for children with special educational needs, including mainstream schools. Given that children with autism have different needs, a range of educational provision is required to meet these, from mainstream school, schools for children with moderate or severe learning difficulties or specialist provision for autism.

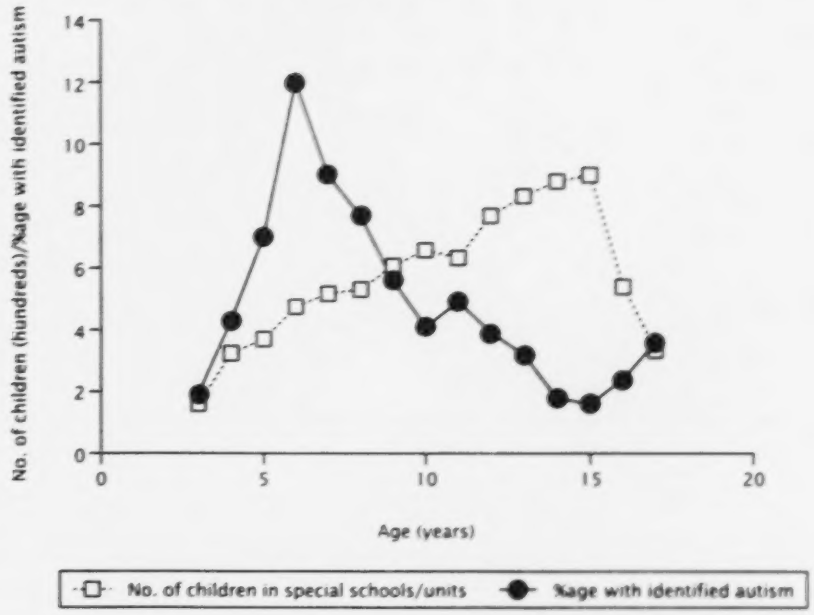
These options may differ on a number of variables including staff expertise and experience in autism; staff-child ratio; the nature and amount of individual teaching; the curriculum and the focus of the work; characteristics of the peer group; the distance from home and the nature of parental involvement; whether they are residential or day; opportunities for spending time with children without autism; access to information on autism or to specialist advisory support; additional therapy and resources ; approaches used; size of classes and of the school; flexibility and differentiation to meet individual needs. All of these may need to be considered when determining the most appropriate placement for an individual. For each type of provision there will be a set of associated advantages and disadvantages but effective liaison and a sharing of resources could serve to reduce the number of disadvantages of each.

Special schools and units not set up specifically for autism

The majority of children with autistic spectrum disorders will attend schools which do not specialise in autism – either special schools and units or mainstream schools. Sixty-three per cent of the 311 special schools and units contacted returned their questionnaire. Of these, 117 (60%) respondents said they had children on roll with autistic spectrum disorders. They identified a total

of 430 such pupils. Fifty-nine per cent of these 117 schools and units said they had children with a definite diagnosis; 60% had children with a possible diagnosis. Overall, the ratio of boys to girls was 4:1, which is in line with the ratios found in other studies. Almost 40% of respondents referred to children as having autistic tendencies. The term "autistic tendencies" may have several different meanings for parents and staff and the professionals who describe children in this way, and as such, is not likely to be helpful.

Figure 2 : Percentage of children with identified autistic spectrum disorders (from the 1996 survey) and number of children in special schools/units (in 1994), by age.



Sixty per cent of the special schools and units which did not specialise in autism had at least one child with an autistic spectrum disorder on roll and 25% of these had more than five children on roll.

The graph shows that the percentage of the special school population comprising children with autistic spectrum disorders increases rapidly in early childhood and reaches a peak at six years. From then, there is a more or less steady decline until mid teens and then a short rise again as school leaving age is approached. This reflects changes in both the general population of such schools and in the age of identification of children with autism.

Some of these schools and units had several children on roll with autistic spectrum disorders, even though they had not been specifically set up or developed to provide for this group. Twenty-eight per cent had just one child on roll; another 48% had between 2 and 5 children on roll; 20% had between 6 and 10 on roll, and 6 schools had more than 10 children on roll.

How can an authority ensure that staff in these schools and units have information and training on the specific educational needs of these children?

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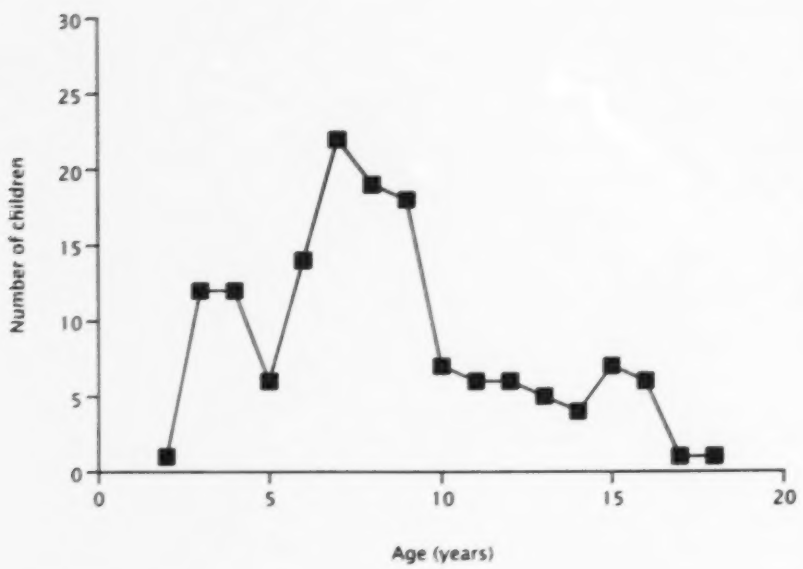
The majority of places in specialist provision were for children of primary age.

What provision should be made for these children at the secondary stage of their education?

Specialist schools and units

The specialist provision for autism in Scotland consisted of three specialist schools, which were well established, and seven more recently established units. There was a total of 156 children on roll. Six of the units catered for primary aged children and one was for secondary aged children; the three schools were all age. All three schools were at least partly residential and the two independent schools were predominantly so; all the units were day units. Most children attending the specialist schools and units were of primary age, as shown in Figure 3, with a small number in the pre-school age group. Many units have only opened recently and are for primary children only – so their first intake has not yet passed through into the secondary phase of education. Planners in these authorities will need to consider the educational response they might make to the leavers of these units in the future.

Figure 3: Number of children in each age group attending specialist schools and units in 1996



Placement in a mainstream school

If children with Asperger syndrome, or high functioning autism, account for a disproportionate amount of children with autistic spectrum disorders, then clearly the majority of such children will be in mainstream schools. There are many potential benefits to such a placement, particularly the fact that they will have access to children with good social and communication skills, a broader curriculum and more able peers than in special or specialist settings. There are, however, potential difficulties for the child, their family and the staff and it is very important that there are regular reviews of placement.

Because of the low returns from educational psychologists, most of the information on this group came from parents of children who already had a diagnosis and a Record of Needs. In these respects, the information was not necessarily typical of children with autistic spectrum disorders in mainstream schools. As diagnostic rates increase, and as educationalists become more aware of autism, and more accepting of its relevance in determining a child's educational needs, so it is to be expected that more children with autistic spectrum disorders will be identified within mainstream schools.

Far fewer children were identified as attending secondary, rather than primary, schools. One of the biggest problems in providing adequate support for pupils with autism in mainstream was the training of the staff providing that support. The most common model appeared to be the use of auxiliaries, sometimes supported in turn by outreach work from a specialist school or unit.

Parents' views

A total of 116 parents completed a questionnaire and a selection was interviewed. Seventy eight per cent had children of pre-school or primary age. Almost as many children were in schools for children with SLD as were in specialist schools or units and there was a range of other settings represented. Fifteen per cent of families had another child who also had a recognised difficulty, including autism, developmental delay or dyslexia. Almost 60% of these children had been diagnosed before the age of five years, this being better than the average for the UK. Some parents, however, found little in the way of information and support until they contacted the voluntary agencies.

More than half the parents (65%) were either satisfied or very satisfied with their child's current education, but 26% were not. Fifty-seven per cent of parents said they had particular concerns about their child's current schooling, largely focused on the lack of knowledge or understanding about autism or on wanting an intervention that was not available. Forty-eight per cent of parents rated their school's understanding of autism as fairly good or good. Forty-one per cent, though, regarded it as only adequate or less so. A very high percentage of families (84%) said they had concerns about their child's future education, very largely because their future placement was uncertain or not known. Links between schools and adult life need to be strengthened and there needs to be better long-term planning, involving all appropriate agencies, at all the stages of transition between primary and secondary schools, and between schools and adult facilities.

Both staff and parents had concerns about future educational provision.

How can an authority address these concerns?

The professionals most often given a rating of 'very satisfied' were from the local autistic society and the pre-school team. Professionals in the position of advice-giving (ie health visitors, GPs and educational psychologists) were rated poorly if they were thought to know very little about autism. Professionals who were in the position of doing direct work with a child generally were rated higher (eg speech therapists, music therapists).

Educational approaches

There were several examples of good practice identified in schools and units which specialised in autism and in other types of educational provision.

However, in some schools and units, staff had little knowledge on how best to work with these children

How can an authority share and disseminate good practice across all schools and units?

Approaches in the schools and units not specific to autism

Two-thirds of these 117 respondents said they took different or special measures with pupils with autism. Some mentioned specific approaches with particular children such as speech therapy; the use of symbols or signs; and drawings, pictures or photographs; music; TEACCH (Treatment and Education of Autistic and Related Communication Handicapped Children); computers; interactive play; teaching pointing; music therapy; the Option approach; movement; the Living Language scheme; and Gentle teaching.

Other comments referred to the teaching style or ethos which was adopted, such as: consistency; structure; clear information about the timetable; familiar staff; minimal or careful use of language by staff; learning in real-life situations; patience; staff flexibility; and a distraction-free environment. There were some examples of very good practice for pupils with autism in these schools, but there were also others, similarly resourced, who were struggling to meet the needs of these children. The latter requested training and support.

Approaches in the schools and units specific to autism

It was encouraging to see that, for most schools and units, single approaches were not being adopted en masse and children were usually offered a broad curriculum incorporating aspects of different approaches to meet individual needs. This eclectic stance, while to be commended, requires a high degree of staff knowledge and expertise in autism, to identify needs and select the approaches best suited to meet them.

There was good practice identified in ways of managing and preventing challenging behaviour and this was characterised by a positive and long-term approach, rather than the adoption of specific control strategies. There was an appropriate emphasis on communication in the specialist schools and units with some good use made of interactive approaches to build relationships and foster communication. Alternative systems of communication to spoken language were being used, although there was variation between schools on whether signs or visual symbols (or pictures) were used.

With regard to the organisation of the learning environment and the actual teaching method used, there was again evidence of a mixture of approaches. TEACCH had had a pervasive influence, but nowhere was using it wholesale as a 'package'. Behavioural methods were also common, but nowhere had adopted a Lovaas-style intensive behavioural programme. There were also elements of 'low intrusion' methods in many schools and some elements of Daily Life Therapy, mainly in daily periods of aerobic activity but also in termly projects with a performance element.

Admission criteria

Admission policy and practice varied considerably and so similar children with autism received different placements and interventions. There is much that one can question and consider in studying this diversity (eg authority policy; availability of certain interventions; relationships between schools and parental action). The situation has been complicated and exacerbated recently by the reorganisation of authorities. This was reported to have resulted in geographical locality overriding other needs-led criteria for entry.

Each authority needs to draw up criteria to guide admissions to schools and units. Linked to this should be a consideration of the criteria to determine when a child should move on to a different placement.

Opportunities for contact with children without autism

There was a range of practices, with most special schools and units inviting mainstream children into their school for some activities. Arranging contact with mainstream children was hardest to arrange for isolated schools, but even those near other schools found that staffing levels, and the changing population of the school, made these opportunities difficult to resource. Contact with children without autism was more common in the units, especially those in mainstream settings, but even here there were significant differences between the units in the relative emphasis given to this compared to providing a specialist environment to meet needs.

Residential provision

Some parents and headteachers of special schools felt there was a need for some residential care to be provided, especially at secondary level. In many cases the need was argued as an educational one, based on the need for a 24-hour curriculum and the teaching of independence skills; respite care was seen as a separate issue. However, some educational psychologists and heads of units argued strongly for more support for children to remain with their families and for home-school collaboration to deliver the 24 -hour curriculum. More creative and flexible ways of providing support for families to enable their child to continue living at home should be explored in the future (eg extension of befriending and shared care schemes; extension of school staff's contracts to enable work at home; development of local residential hostels which offer more time to families than traditional respite care facilities).

Some families required more support at home to meet the child's needs and those of other family members

How can education, health, social and voluntary services work together to plan and provide this?

Resources

There needs to be some notion of funding according to need rather than type of provision and whatever system exists for allocating resources needs to be transparent and open. Schools, however, can be helped to work more effectively

within their resources. Consideration has to be given to the most appropriate staffing for the child and under what conditions enhanced staffing would need to be made for a child with autism in a mainstream school or an MLD or SLD school. This is not a simple matter. Increasing the staffing will not automatically be helpful if the staff concerned are unsure how to support and work effectively with a child with autism.

The other crucial factor in the staffing equation is to assess the resources already available to the school (eg expertise on the staff; external input and advice) and recognise that the child's needs are not assessed in isolation from the school or unit context.

Training needs

The importance of specialised training in autism was stressed in addition to the value of professional development courses rather than single one-off training sessions. The research found a high degree of specialist qualifications in the specialist schools and units with many of the key staff having completed a specialist professional development course in autism. There are increasing opportunities to gain qualifications in autism through professional development courses in higher education.

Most specialist staff were offering training to their colleagues and/or training and outreach support to other establishments. The school run by the Scottish Society for Autistic Children felt that continually responding to crises was inefficient. It was now working more strategically with some authorities to develop relationships with 'partner' schools to whom they could offer a programme of targeted training and support. Some areas were beginning to set up multidisciplinary teams to share expertise in autism and develop practice in this area. All teachers and support staff who are working with children with autism will need specialist training and support. There are a number of training initiatives and networks of support being established which can work to counter the effects of isolation, particularly in rural areas, and enhance practice.

The case for having a service (eg outreach team or unit) which specialises in autism

Education authorities should consider having an outreach service or a unit specifically to support children with autism and Asperger syndrome. Smaller authorities could negotiate to joint fund and share such resources. The prime focus would be to centralise a steady build-up of information on autism, along with expertise on teaching children with autism effectively. Without a specific resource on autism in the form of outreach staff or a unit, the task of accessing information and training becomes much more difficult.

Full report

Further details of the study are in the full report – *Educational provision for children with autism in Scotland* – available from Rita Jordan and Glenys Jones, School of Education, University of Birmingham, Edgbaston, Birmingham, B15 2TT. Price £12-00.

Further reading

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The views expressed in this paper are those of the authors and do not necessarily reflect those of The Scottish Office Education and Industry Department who funded the study.

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